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The Exploration of Patient-Doctor Relationships, Social Support, and Symptom Invisibility among Women with Lupus: A Qualitative Study

by

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ABSTRACT

Systemic lupus erythematosus (SLE), or lupus, is a rare autoimmune disease in which the antibodies that are formed in the body attack healthy tissues and organs. The most prevalent physical manifestation of the illness is fatigue. Fatigue often plagues patients with no warning and without leaving a trace of measurable evidence. The issue of fatigue's invisibility and the difficulties of communicating the experience of fatigue has been shown to impact relationships with friends, family, and physicians. It is important for patients to understand their condition in order to better identify their own triggers, manage their condition, and communicate their symptoms to friends, families, and other medical professionals. The study sought to explore the lived experience of women who have lupus, describe the impact of symptom invisibility on social support and patient-doctor relationships, identify effective strategies in communicating and managing the condition, and describe the broad range of life changes associated with the disease. The study utilized in-depth, semi-structured interviews to gather detailed information from eleven women with lupus. Six overarching themes emerged from the data: difficulties with diagnosis, discovering lupus is a process, managing lupus, social impact of lupus, communicating the experience, and limitations of the healthcare system. Symptom invisibility was not frequently cited as the cause of any interpersonal problems faced by the participants. Rather, the results suggest that the current healthcare system in the United States may not be equipped to adequately care for patients with lupus. This study provides insight for recommendations to patients with lupus and may inform cultural and policy changes necessary to improve healthcare delivery.

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INTRODUCTION

Background

Systemic lupus erythematosus (SLE), or lupus, is a rare autoimmune disease in which the antibodies that are formed in the body attack healthy tissues and organs (Agarwal, Barnes, & Kumar, 2015; Jolly et al., 2012; Pettersson, Möller, Svenungsson, Gunnarsson, & Welin Henriksson, 2010). It is estimated that in the US, SLE affects about 40-50 individuals in every 100,000 (Lawrence et al., 1998), predominately women (9 out of 10). In addition, women of color are 2 to 4 times more likely to be diagnosed with lupus than Caucasian women (Auerbach, Beckerman, & Blanco, 2013; Ortiz-Hendricks, 2012). The disease is marked by a series of exacerbations (flares) and remissions, and also by its unpredictable nature (Agarwal et al., 2015; Auerbach et al., 2013; Auerbach & Beckerman, 2012; Squance, Reeves, & Bridgman, 2014). Although what causes lupus is unknown, researchers suspect that genetic, environmental, and hormonal factors all contribute to the development of the disease (Kyttaris, 2010). The clinical manifestations are caused by inflammatory processes that affect different organs and if untreated may cause permanent damage to organs and tissues, most commonly to the skin, kidneys, or joints (Agarwal et al., 2015; Auerbach et al., 2013; Squance et al., 2014; Kyttaris, 2010). The most common symptoms experienced are joint pain and fatigue which contribute to poor quality of life (Auerbach et al., 2013; Neill, Belan, & Ried, 2006; Pettersson et al., 2010).

Fatigue is typically the most prevalent physical manifestation of the illness, often plaguing patients with no warning, and without leaving a trace of measurable evidence (Auerbach et al., 2013; Kralik, Telford, Price, & Koch, 2005; Neill et al., 2006;

Pettersson et al., 2010; Squance et al., 2014). Fatigue has been described as the most chronic symptom experienced by 50 – 100% of patients with lupus (Del Pino-Sedeno et al., 2016; Kozora, Ellison, & West, 2006). For example, between 80 – 90% of women with SLE (N = 20) reported moderate to severe mental and physical fatigue in the past month (Tench, McCurdie, White, & D'Cruz, 2000). Due to fatigue's chronicity, it is not uncommon for patients to suffer from lupus-related depression and anxiety (Auerbach et al., 2013; Auerbach & Beckerman, 2012; Jump et al., 2005). In fact, a study comparing depression in patients with SLE (n = 87) versus patients with other chronic disorders (n = 78) such as fibromyalgia and heart disease found that those with SLE were more likely to report a diagnosis of depression compared to the control group (40% v. 7%, respectively) (Jolly et al., 2012). In addition, patients with lupus are likely to experience lupus-related depression and anxiety, usually measured using the SLE needs questionnaire (1 = "no need" and 5 = "high need"). Auerbach et al (2013) found that compared to participants who did not experience fatigue, patients who experienced fatigue report significantly higher need for support due to depression (3.2 v. 3.7) and anxiety (3.2 v. 3.8). Overall, the evidence suggests that fatigue impacts patients' mental health thus increasing a need for further assistance.

Furthermore, the fact that fatigue does not have a clear sign nor an objective measure (i.e., it is an invisible symptom), may further impact patients' quality of life. A discussion group of 30 women who suffer from chronic fatigue reported seeming unreliable to friends/family as a consequence of fatigue's invisibility (Kralik et al., 2005). Respondents expressed great difficulty communicating to others how much fatigue affects them (Kralik et al., 2005). The issue of fatigue's invisibility and the difficulties of

communicating the experience of fatigue has also been shown to impact the relationship with physicians (Berrios-Rivera et al., 2006; Hale et al., 2006; Kralik et al., 2005; Street, Makoul, Arora, & Epstein, 2009; Ward et al., 2003). In order to understand the extent of the problem, we will explore the experience of symptom invisibility in different conditions.

Defining Invisibility

A chronic invisible illness is described as an ongoing condition that may or may not be treatable and is often forgotten, ignored, trivialized, dismissed, and/or poorly understood (Jefferies & Clifford, 2012; Vickers, 2000). Disclosing an invisible disease to others does not guarantee that people will understand the experience of having that condition (Hoppe, 2010). Rather, patients might still be subject to ineffective and/or unwanted social support (Brennan & Creaven, 2015).

Invisibility of a disease occurs due to certain nuances unique to that illness which might interfere with a patient receiving proper care (Ciribassi & Patil, 2016; Gysels & Higginson, 2008; Hoppe, 2010; Jefferies & Clifford, 2012). Patients with sickle-cell disease ($N = 70$) reported that their pain, an invisible symptom, is often challenged by healthcare professionals (HCPs). They attribute this dismissive attitude of HCPs to the stereotype that African-Americans, the group most afflicted with sickle-cell disease, abuse drugs. Although doctors often rely on patients' self-report to estimate pain severity, many participants discussed the fact that when they encounter new doctors, their expertise tends to overshadow the patient's expertise on their own medical history; therefore, patients' pain would remain untreated (Ciribassi & Patil, 2016).

Similarly, a qualitative study sought to analyze the lived experience of breathlessness, an invisible symptom, among patients with chronic obstructive pulmonary disease (COPD) and found that many of the participants (N = 18) perceived a lack of response from HCPs due to the fact that COPD is seen as an illness in which the patient is responsible for its occurrence (i.e. because of smoking). For that reason, patients with COPD reported not receiving treatment unless they had an acute episode of breathlessness in front of HCPs (Gysels & Higginson, 2008).

In a study using qualitative interviews to investigate the experiences of thirteen women with cancer of the vulva, Jefferies & Clifford (2012) attribute the invisibility of the disease to the private location of the tumors in addition to the general lack of understanding about vulvar cancer. As a result of suffering a "taboo" condition (i.e. cancer of the vulva), many of the women felt their informational needs regarding their diagnosis and what it entailed were not met. They reported feeling shock when met with physical, psychological, and sexual difficulties following the surgery to remove the tumor(s), and believed they were not sufficiently warned about these difficulties by their physicians (Jefferies & Clifford, 2012). The evidence suggests that "invisible" conditions/symptoms tend to be more difficult to communicate and manage.

Poor Patient-Provider Communication

It is important for patients to understand their condition in order to better identify their own triggers, manage their condition, and communicate their symptoms to friends, families, and medical professionals (Jefferies & Clifford, 2012). In the case of SLE, the educational process seems hindered by a limited understanding of the condition among physicians as well as poor communication practices that harm the patient-provider

partnership (Hale et al., 2006; Kralik et al., 2005; Squance et al., 2014). For example, women with SLE (N = 10) have reported that prior to diagnosis, they felt doctors labeled them as "malingering" due to frequent visits resulting in no new developments (Hale et al., 2006). Once diagnosed, they felt their symptoms were finally legitimized, however, they reported not having an opportunity to sit down with their doctor to discuss causality, treatment, and disease progression. Overall, they believed health care professionals (HCPs) not specialized in SLE lacked a basic understanding of the illness. The authors suggest these issues might occur due to poor communication between HCPs and patients, as well as HCPs underestimating the impact that the unpredictable nature of the disease may have on the patient (Hale et al., 2006).

Squance et al (2014) found similar dismissing experiences among 101 women with lupus. Participants reported that it was likely for lupus flares to be dismissed by HCPs and general practitioners (GPs). Participants speculated that GPs expect the objective flare assessments and the subjective experience of a flare to occur simultaneously. While doctors tend to rely on biomarker measures and treatment changes, SLE patients relied more on the subjective experience of change and will report a flare if there is a new symptom or an exacerbation of an existing symptom. Of the 101 females with SLE in the study, only 25% of them reported they always told their GP when they were having a flare. One fifth (20%) of the women would only tell their doctors if they were already going to see them or if they deemed their flare was severe enough to report (Squance et al., 2014). Participants expressed resignation with the fact that it is difficult to get an appointment with the doctor as soon as a flare occurs, and with

the discrepancy between a patient definition and a doctor definition of a flare (Squance et al., 2014).

Women who suffer from fatigue due to other chronic conditions also believed their physicians had limited knowledge of what it means to experience fatigue (Kralik et al., 2005). This limited knowledge also seems to lead to discrepancies in the definition of fatigue used by patients and their HCPs (Kralik et al, 2005). Although these women considered their experience of fatigue as severe and of significant importance, they often felt HCPs invalidated their concerns and were unable to offer support or treatment. The discounting of their symptoms resulted in internalizing the burden of fatigue instead of reporting their complaints and receiving appropriate medical treatment. Because of their fatigue, participants struggled to maintain concentration during social interaction, which sometimes resulted in social isolation (Kralik et al., 2005).

How Lack of Information Interferes with Appropriate Treatment

Waldron et al (2011) examined eight focus groups of patients with lupus (N = 43), in which participants reported that the lack of information about lupus after diagnosis increased feelings of isolation, because they were unable to effectively communicate their symptoms to their family members. Complaints concerning information about the disease were primarily attributed to the limited information provided without the opportunity to speak to a health professional one-on-one. Patients believed the information they received did not equip them with the knowledge or skills necessary to manage their lupus-related symptoms. In fact, they were unable to recognize what symptoms were indicative of a flare-up (Waldron et al., 2011). Furthermore, some reported they were not informed about the purpose of each medication they were prescribed, which consequently

discouraged them from taking the medication (Waldron et al., 2011). While miscommunication between patients and HCPs has been shown to result in many negative consequences for the patient (Jefferies & Clifford, 2012; Kralik et al., 2005; Raine, Carter, Sensky, & Black, 2004; Squance et al., 2014; Waldron et al., 2011), a positive relationship between the patient and the HCP is integral to promoting better health outcomes throughout the lifetime of women living with lupus (Bennett, Fuertes, Keitel, & Phillips, 2011; Berrios-Rivera et al., 2006; Street et al., 2009; Ward et al., 2003).

Benefits of Positive Patient-Doctor Working Alliance

There is evidence linking a positive working alliance with improved patient health (Anderson, 2002) and lower symptom burden (Little et al., 2001) across various medical concerns (Bennett et al., 2011; Berrios-Rivera et al., 2006; Martin, Jahng, Golin, & DiMatteo, 2003; O'Malley, Sheppard, Schwartz, & Mandelblatt, 2004; Safran et al., 1998; Viller F, Guillemin F, Briançon S, Moum T, Suurmeijer T, van den Heuvel, 1999; Ward et al., 2003). A working alliance between the patient and the HCP intends to promote agreement on treatment goals as well as tasks to achieve those goals through a collaborative approach, which promotes patient trust in the HCP (Bennett et al., 2011). A cross-sectional observational study of adults, employed by the Commonwealth of Massachusetts (N = 7,204), found that patient trust in physicians was one of the stronger predictors of patient adherence (Safran et al., 1998). In addition, another cross-sectional study determined high trust in physicians among low-income African-American women (N = 961) was associated with the use of nine different types of preventive clinical services (O'Malley et al., 2004). Among patients with lupus and rheumatoid arthritis

(RA) (n = 32 & n = 70, respectively), patient trust was associated with physician sensitivity to patient concerns (Berrios-Rivera et al., 2006). Satisfactory communication with HCPs among patients with RA was related to consistently adhering to a medication regimen [OR 0.3 (0.1 – 0.8, p = .03)] and more knowledge about RA and RA treatment [OR 0.4 (0.2 – 0.8, p = .03)] (Viller et al., 1999). An overall positive working alliance between patients with SLE (N = 193) and their physicians was also indirectly related to greater health-related quality of life via treatment satisfaction and directly related to treatment adherence (Bennett et al., 2011). Further, patient involvement in the decision-making process was associated with less organ damage in 68 patients with lupus over a 4.7-year follow-up (Ward et al., 2003). Finally, a clinical encounter with a physician who consistently answered patient concerns (β = .22, p < .01), used open-ended questions (β = .49, p < .001), and offered fewer alternatives versus too many alternatives (β = .21, p < .01), led to patient satisfaction among 128 patients with type II diabetes (Martin et al., 2003). In summary, it is essential for patients to have a positive and collaborative relationship with their physician since extensive evidence suggests such a relationship leads to a number of beneficial outcomes for the patient.

Importance of Social Support

Along with support from medical professionals, there is also evidence that support from social relationships is related to improved mental health status directly and indirectly through stress buffering (Thoits, 2011). For instance, patients with cancer experienced a reduction in anxiety when high social support significantly interacted with high optimism (β = .15, p = .02) (Applebaum et al., 2014). Better mental health is beneficial for patients because evidence has shown it is predictive of adherent behaviors

(McKellar, Humphreys, & Piette, 2004; Thumboo et al., 2000). For example, McKellar et al (2004) used structural equation modeling to confirm a direct relationship between lower depressive symptoms and engaging in diabetes self-care adherence, such as following a diet and medication regimen among 307 women with type 2 diabetes. Specifically, in patients with lupus (N = 90), a 6-month follow-up showed that having greater family support was associated with improved mental health scores (β = 1.77, p = .002) (Thumboo et al., 2000). In patients with lupus (N = 97), (Auerbach et al., 2013) having many friends to rely on decreased the need for support due to depression (β = - 1.70, p < .01) and anxiety (β = - 1.12, p < .05). In addition, severe depressive symptoms in patients with SLE (N = 834) strongly predicted low adherence [OR 1.45 (1.04 – 2.04, p < .001)] (Julian et al., 2009). Overall when patients have a solid social support system, it improves their mental health status (Applebaum et al., 2014; Auerbach et al., 2013; Thoits, 2011; Thumboo et al., 2000). A good mental health status not only improves their psychological wellbeing, but also promotes self-care and medication adherence (Auerbach et al., 2013; Julian et al., 2009; McKellar et al., 2004).

Although social support and positive patient-doctor relationships predict better self-care behaviors (Auerbach et al., 2013; Bennett et al., 2011; McKellar et al., 2004; Safran et al., 1998), the inability of patients with lupus to effectively communicate their symptoms to others may contribute to misunderstandings about the severity of the disease among friends, families, and medical professionals, because lupus symptoms do not always display external clinical signs (Agarwal et al., 2015; Hale et al., 2006; Jefferies & Clifford, 2012; Kralik et al., 2005; Squance et al., 2014; Waldron et al., 2011).

Purpose of Study

This study aims to: 1) describe the lived experience of women who have lupus; 2) describe the impact of invisibility on their perceived social support and patient-doctor relationships; 3) identify effective strategies in communicating their experience with the condition; and finally 4) identify effective strategies on how to manage lupus and the broad range of life changes associated with the disease. To achieve these aims we will utilize a qualitative approach.

METHODS

Study Design

There is a remarkable lack of information about the experiences of women with SLE. Given this limited information available, a phenomenological qualitative approach is ideal to explore and shed light onto the experiences of women with SLE. This method allows the researcher to gather detailed information on each participant and explore their perspectives, as the experts of their own experiences. Qualitative methodology also gives a voice to people whose voices are hardly heard, and provides a foundation for the development of theories and hypotheses based on their reported experiences (Sofaer, 1999). In qualitative studies, the role of the researcher is to facilitate the process in which participants identify their views. During the data analysis process, the views of the participants are subjected to some degree of interpretation; however, the aim throughout the process is to remain faithful to the meanings and intentions of the participants (Creswell, Hanson, Clark Plano, & Morales, 2007).

Individual in-depth interviews are widely used by healthcare researchers to co-create meaning with interviewees by reconstructing perceptions of events and

experiences related to health and healthcare delivery. These interviews are able to inform a wide range of research questions such as what treatment patients with chronic back pain expect from pain treatment centers (Walker, Holloway, & Sofaer, 1999) and why adolescents with food allergies fail to adhere to treatment instructions (Herbert, Lin, Matsui, Wood, & Sharma, 2015). In general, the qualitative approach requires the basic research question to be focused so that a relatively homogenous group will have shared experiences about the topic. The basic question can be followed by 5 – 10 more specific questions to delve more deeply into different aspects of the research issue (Crabtree & Miller, 2002).

In-depth Interview

Interview questions were designed to elicit the experiences along the life-cycle of patients with lupus; starting with the process of being diagnosed with lupus, the initial education about the diagnosis, the challenges of communicating their symptoms to their physicians and members of their social network, the impact of their symptoms on their social interactions, and the key management strategies they devised through the process. Several studies have reported the issue of invisibility as one of the challenges of women with SLE; therefore, we were interested to hear in particular how the invisibility of their symptoms has affected their experiences. Main questions and probes were used to gather this information; the main questions asked them to describe the timeline of their illness, if and how others help them manage their symptoms, to describe the working relationship with their physician, and to share their thoughts about the quality of information they have received about lupus care from HCPs (Appendix C). Understanding and identifying

the successful strategies developed through their lived experiences with lupus could inform educational interventions for HCPs as well as newly diagnosed patients.

Survey

Demographic information to characterize the study participants was collected including: age, race/ethnicity, marital status, employment status, family income, number of members in their family including themselves, a single-item question assessing general self-reported health, age of diagnosis, and what type(s) of lupus they have. Responses for race/ethnicity were left open-ended, allowing participants to describe their race/ethnic identity in their own words. The single-item question used by the Rand Corporation and the CDC assessing general self-reported health asked participants to finish the statement, "Would you say that in general your health is," Poor, Fair, Good, Very Good, or Excellent (Hays & Morales, 2001; Center for Disease Control and Prevention, 2000). However, we did not instruct participants to answer the question in relation to other individuals with lupus or the general population; therefore, it is possible that the reference point for participants varied from person to person.

Measures

To describe disease severity, each participant filled out the **Brief Index of Lupus Damage (BILD) questionnaire** (Yazdany et al., 2011), the **Systemic Lupus Erythematosus Quality of Life (Lupus QoL) questionnaire** (Jolly, 2005), and the **Systemic Lupus Erythematosus Needs Questionnaire (SLENQ)** (Moses, Wiggers, Nicholas, & Cockburn, 2007).

The BILD questionnaire is used to identify organs and functions that have been permanently damaged as a result of their lupus. The more items marked, the higher score of lupus damage (Yazdany et al., 2011).

The Lupus QoL questionnaire is a 40-item survey using a Likert-scale from 1 ("not difficult at all," "not troubled at all," or "not at all") to 7 ("extremely difficult," "extremely troubled," or "extremely often) intended to measure quality of life based on problems with physical health and function, emotional and mental health, bodily pain and fatigue, social functioning, and medical treatment relating to their lupus. Higher scores in each item reflect greater disturbance, thus lower lupus-related quality of life (Jolly, 2005).

The SLENQ is an 85-item self-report scale for lupus patients in which participants indicate what categories of daily living they require a high need of support for, using a Likert-scale from 1 ("no need") to 5 ("high need"). The categories are physical needs, daily living needs, psychological/spiritual/existential needs, health service needs, health information needs, social support needs, and employment needs. The more items marked suggests a higher need for support for the patient (Moses et al., 2007).

Participants completed either a hard copy version of the survey or an online version hosted by Survey Monkey. The surveys completed on paper were entered into Survey Monkey by the researcher.

Sample and Recruitment

An appropriate sample size for a qualitative study is one that adequately answers the research question when new categories, themes, or explanations stop emerging from the data (Crouch & McKenzie, 2006; Marshall, 1996; Patton, 1990). Given the low

prevalence of SLE (Feldman et al., 2013), the exploratory nature, limited resources, and the time constraints of this study, it was estimated that we needed to recruit 10 – 20 key informants from a convenience pool of women 18 years or older with a confirmed diagnosis of lupus for at least one year. We believe one year of a confirmed diagnosis of lupus would be sufficient for participants to have a breadth of experience with the disease and with patient-provider interactions. Males and adolescents under the age of 18 were excluded. The final sample included 11 women with lupus meeting those criteria. After interested participants were identified, they read a consent form and stated their verbal agreement preceding the interview. The interviews were audio-recorded and conducted either in person at a public location or over the phone. Following the interview, each participant filled out a questionnaire.

Procedure

Each interview was transcribed verbatim by the researcher. The information from the audio-recordings was linked to the matching questionnaire by using a participant ID. Each transcript was read and annotated repeatedly. After first impressions were made, labels for codes emerged that reflected more than one key thought. Related codes were then collapsed into meaningful topics. This process was repeated until the researcher (MVB) and research mentor (PV) corroborated the overarching themes from the data. The study was approved by Arizona State University's institutional review board.

RESULTS

Participants

The sample included 11 women with lupus; ten participants had SLE, one out of those ten participants had lupus nephritis in addition to SLE, and one other participant

had cutaneous lupus erythematosus (CLE). Since the symptoms and patient-provider experience of the participant with CLE were comparable to the experiences faced by the rest of the women with SLE, she was included in the analysis. Ages ranged from 18 – 65 (M = 34.36, SD = 16.27), and the number of years since diagnosis ranged from 2 – 13 (M = 5.64, SD = 3.83). Seven out of the eleven participants were non-white or of mixed race. Three out of the eleven interviews were conducted over the phone. The results from the BILD questionnaire indicated only three participants reporting bodily damage caused by lupus; one reported an episode of transverse myelitis, another reported an episode of transverse myelitis, seizures, and a cataract, and another reported a cataract. Scores on the Lupus QoL ranged from 53 – 185 (M = 114.45, SD = 46.07), and scores on the SLENQ ranged from 45 – 178 (M = 92.91, SD = 46.33). A total of six participants scored above the mean on the Lupus QoL and four participants scored above the mean on the SLENQ, suggesting lower lupus-related quality of life and a higher need for support due to lupus. In addition, only two participants scored at least one standard deviation above the mean in both the Lupus QoL and the SLENQ. The complete survey results can be found in Table 1.

Data Analysis

Six overarching themes with several subthemes emerged from the data: 1) **difficulties that accompanied a formal diagnosis of lupus** included three subthemes 1.1) delay of diagnosis, 1.2) getting misdiagnosed with another condition, and 1.3) having to fight to receive a diagnosis; 2) **discovering that lupus is a process** included 2.1) experiencing fatigue and pain regularly, 2.2) learning that lupus makes one's life unpredictable, 2.3) feeling inadequate and/or depressed, and then 2.4) accepting one's

own limitations; 3) **managing lupus** requires 3.1) planning activities and life events ahead of time to care for symptoms, 3.2) listening to one's own body (i.e., recognizing when it is time to rest), 3.3) dealing with the limited amount of information on lupus and lupus self-care, 3.4) learning to navigate the Internet to find information about lupus and lupus self-care, and 3.5) learning about the condition via other patient experiences; 4) the **social impact** of having lupus involves patients receiving both 4.1) instrumental and emotional social support, but also 4.2) facing the consequences of others being uninformed about lupus; 5) **communicating the experience of lupus** involves 5.1) educating others about lupus and 5.2) relating the information in ways others who do not have lupus can understand (e.g. spoon theory; Miserandino, 2003); and finally, 6) **limitations within the healthcare system** includes patients having 6.1) difficulties getting doctor appointments ahead of time, 6.2) facing problems with doctors, 6.3) having to find new doctors, and 6.4) developing a partnership with current doctors. The findings are presented in Table 2 by themes and subthemes.

Difficulties with Diagnosis

The participants described challenges they faced throughout the process of being diagnosed with lupus. In general, it is rare to have an official diagnosis of lupus as soon as symptoms occur because symptoms such as fatigue and pain can pertain to a number of different conditions. As a result, many of the participants reported a delay between seeing a physician for lupus-related symptoms and being formally diagnosed with lupus:

> *"They thought that it was a number of things before they thought that it was lupus…So I was actually not formally diagnosed with lupus until I was 16 which is about 14 years later and it was about four or five doctors later."* (Participant 9, age 23)

After two years of experiencing severe symptoms, Participant 7 (age 19) stated,

> *"…[the doctor] diagnosed me with lupus and said I've had it for a long time…"*

Other challenges included some trial and error with the diagnosis or patients being misdiagnosed with other conditions:

> *"I would see a neurologist and the neurologist thought it was multiple sclerosis, and he said I had MS-like symptoms but nothing concrete. So he just said 'Oh, it's fibromyalgia.'"* (Participant 3, age 34)

After going to the hospital due to severe pain, Participant 5 (age 21) reported,

> *"…they thought I was in a car accident, or that someone or something had hit me…but at the same time there was no injury."*

Some of the women also described their experience of having to insist for doctors conduct more blood tests:

> *"…[my doctor] found [having lupus] a bit far-fetched and you know I told her…just humor me."* (Participant 4, age 50)

> *"…leading up to the diagnosis…it took a lot of fighting on my part to actually keep going to doctors because I said, 'No, I know something is wrong with my body, there is something wrong.'"* (Participant 7, age 19)

Discovering Lupus is a Process

Following the process of being officially diagnosed with lupus, participants described the progression of their disease along with the struggles they have faced when experiencing new or existing symptoms. As a whole, participants suffered from fatigue and/or pain regularly:

> *"It's the strangest feeling to just be asleep for 12 hours and you just cannot get yourself up and going."* (Participant 2, age 42)

> *"…there's no day without pain…right now my hand is practically asleep because…I woke up with a lot of shoulder pain."* (Participant 5, age 21)

Some participants also reported dealing with a sense of uncertainty in relation to living with lupus:

> *"… I never know if I'm sick like normal sick or if I have the cold or flu or whatever [or] if it's the lupus."* (Participant 1, age 28)

> *"[The most challenging aspect is] not knowing what day is gonna be a good day and what day is gonna be a bad day."* (Participant 4, age 50)

In addition to dealing with uncertainty, the participants' adjustments to the limitations placed on their lives because of lupus varied. Some expressed the challenges of managing lupus properly and lamented the loss of their previous life:

> *"…you have no control over your body, you're sick more often it seems, you're suppressing your immune system but also trying to boost it, I mean it goes back and forth."* (Participant 2, age 42)

> *"So I went from doing all kinds of adventurous things to just doing nothing, just spending days lying in bed. I used to read a lot of books and research places to go, things to do and…it stopped."* (Participant 3, age 34)

Others communicated feeling inadequate because they are unable to do the things they want to do:

> *"Well sometimes the sleeping in makes me feel like I've wasted my day, which is kind of a hit on my self-esteem."* (Participant 11, age 23)

> *"I feel like I want to do things and I just can't do them. And it seems to me I am being lazy and that's why I can't do them and so that's not a very good feeling. Why am I so lazy?"* (Participant 8, age 65)

Four participants explicitly reported having experienced depressed feelings as a result of the limitations placed on their lives because of lupus:

> *"Well most of the time I continue doing my everyday things…but I look tired, very tired, and sometimes I get depressed…because my body is telling me to stop."* (Participant 6, age 55)

> *"…I got really depressed because it kinda sucked. I was told that I couldn't do a lot of things anymore; I'd have to go on all these medications…"* (Participant 11, age 23)

Not surprisingly, most participants described struggling coming to terms with the life-changing diagnosis:

> *"I feel like I'm never gonna have my life back and I, realizing that this is the best it's gonna be, it's never gonna go back to where I was, where I had lots of energy, I think that is the worst part is accepting that things are not going to be the same"* (Participant 2, age 42)

> *"…you're never gonna get better, there is no cure, you know the best you can do is be on medication for the rest of your life to manage it but you know you'll always have it. And then trying to find purpose in life after that."* (Participant 11, age 23)

On the other hand, a couple participants noted that being limited simply means finding an alternative path to achieve goals:

> *"…you can do anything like anybody else. It's just you can do it differently."* (Participant 5, age 21)

> *"…you can still be everything you've always wanted to be, and you can do all of the things you always wanted to do. They just may not happen in the time you want them to."* (Participant 11, age 23)

Managing Lupus

Although lupus requires major life changes, the women discussed the ways in which they coped with their new obstacles; overall, many of the participants had to learn that stress plays a huge role in the onset of a flare-up. In addition, participants explained how they must keep in mind that flare-ups are always a possibility, meaning they must plan to be sick. For some, this may be something simple such as avoiding outdoor activities:

> *"…just staying out of the sunlight [helps me to avoid flare-ups] because…the sun really irritates my skin."* (Participant 9, age 23)

> *"I have to decide how warm is the day or how cold is the day, how warmed up are my joints in order to do something like [bike riding]. People will say, 'well let's go for a hike,' I know I'm out."* (Participant 4, age 50)

Sometimes planning to be sick requires deciding against a big life change:

> *"I actually didn't go to college with my scholarships that I got [for]this college in Michigan because I wasn't feeling well and they had like the worst winter that*

> *year too. So my parents were scared that I would go and not know what's going on with my body."* (Participant 5, age 21)

All participants reported that relaxing or "taking it easy" was their first line of defense when they felt a flare-up coming on. However, it is a learning process figuring out how to recognize triggers and knowing when to stop and rest, or as Participant 1 put it, learning to "listen to your own body."

> *"…if I know that I'm not feeling well, then I try not to make any plans like social plans or any other kinds of plans I just…basically plan to rest."* (Participant 1, age 28)

> *"Knowing from the beginning what's causing pain [is important] because your body is like a machine. You put something in and…something's gonna come out, so knowing what [is] causing [flares] – for example I cannot be in the sun."* (Participant 5, age 21)

Since it takes more than intuition to learn about one's own body, Participants 2 and 9 recommended keeping track of symptoms in a journal. This aided in making connections between past symptoms and current triggers:

> *"I keep a record of what went on because what you find is…you may have been having symptoms and you didn't even know it…[write] your flares and what you think may have triggered it I mean I wrote all my stuff down…sometimes things are related that you don't realize are related so you write everything down"* (Participant 2, age 42)

> *"…definitely keeping a journal I think is really helpful. There is some stuff that I was curious about so I just had a notebook…I was curious so I started documenting [my menstrual cycle] and then there was a clear link between them."* (Participant 9, age 23)

Even so, participants are not likely to always have an explanation regarding their own flare-ups or symptoms. Therefore, they commonly use the Internet as a source to either find the cause of their symptoms or how to manage them. Yet they still encounter difficulties navigating the Internet whether for lack of information about lupus or for having to sift through poor-quality information:

> *"Sometimes I look online but it's hard to look online when there's a lot of [crap] online."* (Participant 1, age 28)

> *"…maybe it's because lupus is an enigma, I mean there are so many symptoms in people and so many different things going on. I find it hard to find any good information."* (Participant 2, age 42)

> *"[Websites] say okay [lupus] attacks your organs, and you can have this, but so many…sites act like you just have this big scar on your face that you just have to deal with because they say 'Oh but many people with lupus just go on with their lives and have fulfilling lives,' like they don't tell you what really happens through this."* (Participant 3, age 34)

> *"Do not…do research online, if you say you have a headache…they are telling you that you're dying too."* (Participant 5, age 21)

> *"…it's like really hard I think, even though the lupus foundation does have a lot of information and a lot of different articles and about all types of things with lupus, it's still not enough because I mean the problem is there's not enough research"* (Participant 10, age 18)

Because of the difficulties finding information on the Internet, some participants reported benefitting from learning about other patient experiences:

> *"Get to your nearest local support group. I think they are so informative. I've been a nurse for almost 25 years but…I knew nothing about lupus."* (Participant 4, age 50)

> *"…I had to go to [lupus] support group meetings to see people in wheelchairs…You know you have to find out from our lupus support group facilitator, I didn't know you could end up in a coma, I didn't know all these other things could happen"* (Participant 3, age 34)

While most participants found information from other patients with lupus, Participants 5 and 6 recognized the fact that certain lupus manifestations can resemble other conditions; thus, they looked up what patients with other chronic illnesses do to treat their symptoms:

> *"Honestly I get my information from other diseases…[I look up] exercises for rheumatoid arthritis patients or stuff like that... I have a lot of joint pain and a lot of muscle pain so…I look up, for example yoga, how [you can] stretch…or what types of exercises for muscle pain or chronic pain and skin problems like with rashes, how to prevent, stuff like that. I don't really look up lupus."* (Participant 5, age 21)

> *"[Side-effects] can affect my heart or my bones or my kidneys so I read about those other illnesses…"* (Participant 6, age 55)

Social Impact

In addition to their own self-care behaviors, participants reported sometimes requiring outside assistance to help manage their condition, such as receiving the help from friends and family. Participants who reported that friends and family helped them did so by allowing them to rest, making their work-load lighter, being available for emotional support, and validating their concerns:

> *"…they just do…everyday things for me. Like bring me food or just be around to take me to appointments or the hospital or whatever…it helps that they aren't mad when I'm not able to do things. And they understand if…I can't do [activities], I'm just gonna sleep [that] day."* (Participant 1, age 28)

> *"My husband [understands] because he…has lived with me all his life so he knows how I was and how I am…he will try to take care of things that I can't do. Like things around the house like the wash or he'll do the dishes."* (Participant 8, age 65)

> *"[My friend] will kind of talk me through [my flare] and just let me vent and let me talk about it and then usually once I talk about it, it gets easier…the most helpful thing is just support. 'Okay I'm here for you, if you want to vent go ahead.' Or if I am with them just sometimes sitting with me or hanging out with me in bed or doing little things…"* (Participant 7, age 19)

Participant 2 (age 42) found that having someone to try new self-care activities with proved to be helpful as well:

> *"Well my mom, she looks out for me…we do things together like a diet change and we…try this thing, see if it makes us feel better. So that's someone who's willing to make changes with me and then we test it on each other."*

However, because of the drastic changes that follow a lupus diagnosis, it is not surprising that some family/friends have trouble understanding the experience:

> *"…they forget that sometimes I'm tired and I need to stay home. Even if I want to go out, so sometimes they don't understand that. And I try to explain it to them; I*

> *tell them to go even if I don't feel well. And so I don't know if they really understand how a person with lupus feels because they don't have it."* (Participant 6, age 55)
>
> *"…people [think] that you're better now, well I'm better yeah but I'm not yet well."* (Participant 8, age 65)
>
> *"… just as I can't fathom people not having pain, normal people can't fathom having pain all the time."* (Participant 11, age 23)

A few participants spoke about situations where these misunderstandings led to family/friends being insensitive to the fact they have limitations:

> *"My mom was like 'you're not better yet? I thought that would be done already. Why are you still walking like that?' and…'Oh my friend of a friend has lupus and she's skinny…you can't tell she has lupus, she doesn't walk with a cane…'"* (Participant 3, age 34)

While the literature suggested patients might have problems with social support due to symptom invisibility, there were only two participants who explicitly stated that this was distressing to them:

> *"I think the biggest thing is people say, 'well you look fine, so you must be fine.' And that is probably my biggest trigger for getting me upset because [lupus] is an invisible disease and I am in constant pain. But lupus patients and anyone with an invisible disease have learned how to fake it. Because if you don't fake it, people aren't gonna wanna be around you."* (Participant 7, age 19)
>
> *"The 'you're so young, you can't have disorders' you know I have a handicapped placard for my car, the looks and stuff you know…sometimes for people with invisible illnesses like that, just getting up in the morning is their biggest accomplishment of the day."* (Participant 11, age 23)

Communication

As previously stated, communication is an important tool for conveying information to others so they may understand the experience of having lupus. The participants discussed ways in which they effectively communicate their experience to

others. Some participants noted that in order to communicate in a way others could understand, they had to find their own phrases or words that were compelling to them:

> *"Find those phrases that become meaningful to you and your friends or your family so that you kind of, not like your own language but like you have your own subtext."* (Participant 11, age 23)

> *"…really keep it simple. 'Autoimmune' was really the key word for me. And then some simple identifiers of how it affects them."* (Participant 9, age 23)

Some reported that simply educating others and being honest about their experiences was enough to get people to understand, while others utilized analogies to make the experience more relatable to the general population:

> *"…what I do, it's like you're having the flu but without mucus and coughing. Your body feels like that, aching the whole time, but I also tell them it's like having a bruise and you can't touch it."* (Participant 5, age 21)

> *"I tell them it's basically like when I have the swelling and pain in my legs, I try to say it's like having a huge mosquito bite in the back of your knees or I tell them it's like being pregnant and having all the worst symptoms of pregnancy."* (Participant 3, age 34)

Participants 10 and 11 discussed using the "spoon theory" to explain the experience of having lupus to other people. The spoon theory primarily illustrates the act of having to plan each action ahead of time and sacrificing simple day-to-day activities so as to not over-exert the body (Miserandino, 2003):

> *"…with lupus you wake up in the morning with [for example] 15 spoons. And everything that you do takes off one spoon. Getting up out of bed and getting dressed, that's a spoon. Making your breakfast, brushing your teeth, that's a spoon. And at the end of the day you have one spoon left. And so in my house I have three roommates, I'll come home and my roommate will come in my room and she'll ask me, 'how many spoons do you have?' I'm like 'well I don't know, one or two why?' She says 'Well I wanted to go out shopping. Do you wanna come with me?' And I'm like 'yeah I guess.' And then some days I'm just like 'I'm going to bed', and she says, 'Oh no spoons, okay.'"* (Participant 11, age 23)

Limitations with the Healthcare System

The spoon theory and other analogies were useful for explaining the experience of having lupus to friends and family members. However, barriers regarding communicating with physicians seem to be distinctly different than the ones patients face with the individuals closest to them. Because patients with lupus often have symptoms they do not understand, it is important for them to maintain constant communication with their healthcare team, which often includes several different types of doctors, including but not limited to their primary care physician, rheumatologist, neurologist, cardiologist, and dermatologist. Yet some women reported difficulties getting appointments with doctors once concerns would arise:

> *"…just waiting for the doctors [has been challenging] because sometimes I don't feel well and I'm like well I need blood tests, I need doctors to look at me, I need this taken care of, and I have to wait for an appointment or whatever and I don't want to wait I just want to be taken care of immediately."* (Participant 1, age 28)

> *"…the pain in my hands and my wrist was so bad that I couldn't even brush my teeth and I had to go from nothing to something I knew I had to get in. And you know to get into see a rheumatologist...it takes 4 to 5 months to get in if you're a new patient…"* (Participant 2, age 42)

Aside from it being difficult to get an appointment with physicians, Participant 8 (age 65) also described the struggle of receiving information from doctors at certain time-points:

> *"…if I call in between it's difficult to get information in between appointments."*

However, once participants were actually able to meet with their physicians, all voiced concerns about a multitude of issues ranging from a lack of communication, a lack of treatment, and a lack of respect coming from the physician. Participant 2 (age 42) describes her experience of a physician failing to inform her about simple treatments that would help with common lupus symptoms:

> *"I had to do some research and then I had asked her to check my vitamin D…and it was significantly low…I found just by taking vitamin D I saw a lot of improvement that she didn't, that should be like the first thing you ask…I'm like losing all this hair and [my doctor just said] 'oh just take folic acid.'"*

Participant 3 (age 34) discussed a time when her doctor delayed reporting the results of a test, which interfered with treatment:

> *"So months later…I finally get to see the MRI results…which means I finally get an appointment with the orthopedic surgeon because I couldn't see him until I had the MRI. And he does x-rays and he says there is nothing we can do for you."*

On top of not receiving treatment, some participants had mentioned wanting different types of information than what doctors were providing them, mainly concerning lifestyle and dietary information that could improve patient health from day to day:

> *"…something else that I wish the doctors would explain…or maybe understand better, was the impact that food has on lupus and stress but also taking care of your body, your stomach."* (Participant 2, age 42)

> *"…[doctors] tell me what medications to take and how to take them and everything like that. But in terms of…living a healthy lifestyle, none of them have ever said anything. So I kind of just figured it out on my own."* (Participant 1, age 28)

> *"I haven't received a lot of information [from healthcare professionals] other than maybe if I was switching medications or they say 'Okay this is this new medication, this is what it does', otherwise I really had to figure out most of it on my own through my own research."* (Participant 7, age 19)

Participant 1 (age 28) described a time when a doctor did not address her concerns as she would have liked, and speculated that collecting blood samples would have been a better alternative:

> *"I knew I was getting a flare-up, and I went to a doctor, a rheumatologist, and told him all of my symptoms, which were quite a good amount of them…and he prescribed me pain medication and that was it. He didn't order blood tests…with lupus…I think you have to take a look at what's going on inside, you can't just go off the symptoms."*

A few participants also encountered some physicians making inappropriate comments to them:

> "*I had doctors accuse me of things and tell me that this was in my head and it was psychological and it wasn't actual pain*." (Participant 7, age 19)

> *"I don't care how good the doctor is, if I cannot talk to them then you know it's no good to me…I went to the doctors and he says 'what are you doing here?' Yeah obviously I didn't go to see his face…and then pay him for it too."* (Participant 8, age 65)

> *"I recently saw a cardiologist that the first 20 minutes of our appointment was him talking about how lupus doesn't exist, and how it's all stress, et cetera. That's pretty brutal…having people talk about the illnesses I have as if they're all made up is rough."* (Participant 11, age 23)

Overall, a resounding piece of advice from the participants was if a patient is unhappy with a particular physician, they should not hesitate to find a new doctor. Furthermore, a few participants noted that acknowledging the fact that patients are the experts of their own health history can be effective in ensuring that they push for doctors to treat their symptoms:

> *"…keep pushing for the doctors to do the blood tests and give you medications because a lot of times they just don't…They think they know more than you and I know they're doctors and they went to school but they don't feel what you feel so like we're not making it up. So just insist on getting the blood tests and the treatment."* (Participant 1, age 28)

Moreover, participants described ways in which they partnered with at least one of their doctors. Once again, a few participants cited keeping a document of one's own medical history, including symptoms, to show to their physicians. This allows for nothing to be left out and ensures that doctors are receiving all the information necessary about a patient's symptoms even if the symptoms occurred prior to the actual appointment:

> *"Keep a journal of all your symptoms and what the doctors say and the test results…because you have to every time you need a new doctor or whatever they*

> *make you tell it over and over and over, and sometimes you leave stuff out or they don't understand."* (Participant 3, age 34)
>
> *"…whenever I have a new symptom or have pain or my joints swell up, I take a picture or I write it down. And then almost always I bring a list and it's helped the relationship over the years a lot just so [my doctor] knew exactly what I was feeling on this day or he could see 'okay this is what you're talking about when you said it was swelling.'"* (Participant 7, age 19)

Although some participants expressed concerns about the difficulties with getting an appointment with a doctor at the time symptoms flared up, a few were able to circumvent this issue by contacting their doctors via telephone to call at any time with questions or concerns without having to make an appointment:

> *"…[my doctor] gave me his cell phone number and his home phone number so that if anything was ever wrong, I could call him at any time."* (Participant 1, age 28)
>
> *"…[my doctor] is available by phone, I can call her with questions, she gets back to me within 24, 48 hours."* (Participant 9, age 23)

All patients agreed that if doctors treated them with respect, it helped to develop a stronger partnership. The patient-doctor relationship also improved when patients had a say in their treatment options:

> *"…[my] doctor was like, 'Okay you have this option, and this option. This option is this, and this option is that, I recommend this option, but I know you're gonna choose this one.' So it's like that because he knew me, so just having that relationship…he really wanted to help me out."* (Participant 5, age 21)
>
> *"…I've dealt with this for over a decade so it's not like I don't understand my disease or my body so it's very nice to be in control of my own health plan."* (Participant 11, age 23)

Finally, some participants described an affinity to doctors who were able to speculate about their health outside of their respective discipline, thus being able to treat the patient's health more globally. Because lupus is a condition that affects the entire body, it is not surprising that patients would find this trait in a doctor desirable:

> *"…nephrologists just deal with…kidneys, so even stuff that had nothing to do with kidneys, he was really knowledgeable about and he would help me and prescribe me whatever."* (Participant 1, age 28)

> *"…[my doctor] said, 'Your bloodwork is really good, but…you seem really stressed out and anxious so you need to get that under control and everything else will come.'"* (Participant 2, age 42)

> *"…if [my doctor] thinks my depression is getting the best of me she's the first one to be like, 'We need to alter your medications a little bit to help you' or 'You need to go see a counselor,' something like that. She's a very rounded physician knowing that medication is not the only answer."* (Participant 11, age 23)

DISCUSSION

This study sought to explore the lived experiences of women with lupus using a qualitative approach, specifically, the experiences of dealing with patient-doctor relationships, perceived social support, and symptom invisibility. An additional goal of the study was to uncover self-management practices developed by women with lupus along the timespan of their condition, starting when symptoms were initially experienced prior to the formal diagnosis, including the specific barriers they encountered, the strategies they developed to solved them, and their recommendations for newly diagnosed women with lupus. From the testimonials, we identified six overarching themes: difficulties that accompanied a formal diagnosis of lupus, discovering that lupus is a process, managing lupus, the social impact of having lupus, communicating the experience, and limitations within the healthcare system.

Consistent with previous research reporting that a diagnosis of a chronic condition is often accompanied by feelings of shock and confusion (Hale et al., 2006; Jefferies & Clifford, 2012; Kralik et al., 2005), our participants described a challenging process of being diagnosed with lupus. Also consistent trends with previous research, we found a general lack of awareness regarding lupus and its progression, a lack of information

available on lupus and lupus management, and issues managing relationships with physicians (Auerbach et al., 2013; Del Pino-Sedeno et al., 2016; Hale et al., 2006; Tench et al., 2000; Waldron et al., 2011). Regarding social support, participants reported benefitting from instrumental social support (e.g. friends/family helping with activities of daily living) and emotional support (e.g. having someone who will listen to and/or validate feelings). Although we were not able to confirm such relationships, there is evidence that such forms of social support are related to reduced disease activity and damage, and improved quality of life among patients with lupus (Mazzoni & Cicognani, 2011). However, even for those who receive social support, educating family/friends who do not understand the challenges of having lupus remains a major issue in the life of women with lupus.

While many challenging aspects in relation to having lupus were cited, a substantial portion of them included problems with the healthcare system, including physicians. These issues were prevalent throughout the lives of these women battling lupus, including early on when they were being diagnosed, when they were learning how to manage the condition, and when flare-ups arose.

We did not identify potential explanations for poor patient-doctor relationships; however, previous studies suggest in some cases patients with chronic conditions faced difficulties with some physicians because of biases HCPs hold against specific patient characteristics or conditions (Ciribassi & Patil, 2016; Gysels & Higginson, 2008; Raine et al., 2004). Although previous research suggests patient-doctor relationships and social support might be affected by symptom invisibility (Hale et al., 2006; Kralik et al., 2005; Squance et al., 2014; Waldron et al., 2011), it is important to note that the majority of the

participants in this study did not explicitly mention symptom invisibility as the cause of any interpersonal problems faced.

A major concern among the study participants regarding HCPs was the fact that doctors did not fully address patient symptoms, potential management options, and side effects. In addition, some participants expressed concerns about not being able to schedule appointments soon enough even if their symptoms warranted a doctor visit. For a typical healthy patient, Urgent Care Centers and Walk-in Clinics might be an option; however, such establishments seldom have the resources to deal with patients who have lupus. These issues may suggest that currently, the medical system is unable to adequately care for patients with lupus.

The Chronic Care Model (CCM) was developed as a framework for interventions in the healthcare system to manage patients who suffer from chronic conditions, including lupus. The CCM's goal is to help patients become informed and active participants of their health, and collaborate with a prepared and proactive healthcare team (Adams et al., 2007; Barr et al., 2003; Glasgow, Tracy Orleans, & Wagner, 2001; Moullec, Gour-Provencal, Bacon, Campbell, & Lavoie, 2012; Strickland et al., 2010). To achieve this goal, healthcare organizations must improve the clinical information system, as well as the resources to improve decision making, self-management, and linkages to pertinent community resources (Glasgow et al., 2001; Strickland et al., 2010). In addition, the whole healthcare team must be willing and prepared to deliver such care (Glasgow et al., 2001; Strickland et al., 2010).

The few examples of partial implementation of the CCM into medical systems has shown positive results in the management of patients with various chronic conditions

(Adams et al., 2007; Moullec et al., 2012; Strickland et al., 2010). For example, via secondary data analyses from 25 different medical practices, Strickland et al (2010) found that patients with diabetes were more likely to obtain suitable diabetes care if they came from medical practices that utilized elements from the CCM. Similarly, reports from a systematic review support that using the CCM as a framework to inform healthcare delivery improved adherence to inhaled corticosteroids among adults with asthma (Moullec et al., 2012). Finally, another systematic review found that incorporating at least two principles from the CCM in practices treating patients with COPD was related to fewer emergency room visits, a lower likelihood of being admitted into the hospital, and shorter hospital stays, compared to patients who were in medical practices that did not incorporate such components from the CCM (Adams et al., 2007).

In addition to the core elements originally proposed in the CCM; researchers proposed the Expanded CCM to address other factors that might influence health outcomes, such as a person's cultural, environmental, and economic background. The Expanded CCM also incorporates community health promotion to develop the skills necessary to better control outside influences that contribute to poorer health in sick and healthy individuals alike. An example could be the community advocating for greater accessibility in homes, public transportation systems, and buildings to improve the quality of life for the elderly and for other individuals with physical disabilities (Barr et al., 2003). Such improvements in the community and the medical system may considerably help those with lupus; especially because the process to meet such improvements includes keeping patients informed, developing a culture in which

"healthy" individuals are familiar with the various obstacles others face on a day-to-day basis, and encouraging a positive patient-doctor working alliance.

Although not yet tested, it has been suggested that drawing from elements of the CCM would benefit patients with lupus (Williams, Ortiz, & Browne, 2014), particularly because women of color, at higher risk for lupus, are often subject to health disparities (Auerbach et al., 2013; Gillis et al., 2007; Ortiz-Hendricks, 2012; Williams et al., 2014). For example, studies have shown that patients with lupus who use Medicaid travel longer to see their rheumatologist, thus are more likely to see a GP and also more likely to visit the ER (Gillis et al., 2007; Williams et al., 2014). Thus, adopting components from the CCM into community and healthcare systems could potentially improve the quality of life of patients with SLE by addressing barriers concerning travel and accessibility (Williams et al., 2014). A positive impact in the quality of life is also likely if preventive approaches rather than short-term treatments for acute flare-ups are incorporated in the management of lupus (Williams et al., 2014).

Finally, it is important to note that changes that better inform patients about their condition, would address several concerns mentioned by the study participants. For example, many reported learning through experience, instead of through their HCPs, that stress triggered flare-ups and about simple treatments that could help common lupus side-effects (e.g. taking folic acid for hair loss). Although each patient case is unique, there are enough commonalities between the study participants to suggest that more information should be provided about lupus to the patient upon diagnosis. The current study provides recommendations to newly diagnosed patients with lupus that may help them avoid some

confusion that accompanies managing a new condition and urges doctors to educate patients about self-care treatments earlier on.

Conclusion

The study utilized in-depth semi-structured interviews to collect the data, therefore it is inherently subject to a number of limitations. First, there was a small sample size and responses were self-reported, which means that these findings may not be generalizable to the rest of the patient population. Second, the participants in the study were not random; a handful of them were either acquainted with the researcher or shared a mutual acquaintance with the researcher. Third, participating in an in-depth semi-structured interview is a fairly involved process. It is possible that our sample is particularly proactive in many aspects of their lives including with their health, which provides another reason for why we should not generalize these findings to the rest of the population. Fourth, due to the time constraints placed on this study, we could not continue collecting data from participants; consequently, we did not reach data saturation.

Despite these limitations, this study provides new insightful recommendations that if incorporated into clinical practice, may not only help patients with lupus, but other patients as well. For example, maintaining a document to keep track of symptoms and learning from patient experiences outside of one's own condition are some ways patients can participate in useful self-care strategies. These changes aim to benefit patients who are in need of care throughout their entire lives and who must be educated on how to independently manage their own health.

In addition, these recommendations may inform cultural and policy changes necessary to improve healthcare delivery, including how HCPs may improve

relationships with their patients. Finally, future research should confirm the current findings and focus on discovering effective ways to best implement these changes as well as the effect of potential interventions incorporating these recommendations for the treatment of and the quality of life of patients with lupus.

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APPENDIX A

PARTICIPANT DEMOGRAPHICS

Table 1. Participant Demographics

Characteristic	*Number*	*Percent*
Current Age		
18-25	5	45.5
26-34	2	18.2
35-42	1	9.1
50-65	3	27.3
Years since Diagnosis		
2 – 5	7	63.6
6 – 9	2	18.2
10 – 13	2	18.2
Race/Ethnicity		
White/Caucasian	4	36.4
Hispanic/Latina	3	27.3
Black/African-American	1	9.1
More than one race/ethnic identity	3	27.3
Relationship Status		
Single	3	27.3
In a relationship, not living together	3	27.3
Married	4	36.4
Previously married; now divorced	1	9.1
Employment Status		
Employed full-time	3	27.3
Employed part-time/Full-time student	1	9.1
Homemaker	2	18.2
Full-time student	4	36.4
Employed full-time/On disability	1	9.1
Combined Family Income		
$10,000 or less	2	18.2
$10,001 - $20,000	1	9.1
$30,001 - $40,000	2	18.2
$40,001 - $50,000	1	9.1
$50,001 - $60,000	1	9.1
$70,001 and up	3	27.3
I do not know/Refuse to answer	1	9.1

Table 1 (continued). Participant Demographics

Characteristic	*Number*	*Percent*
Number of Members in Household		
1	4	36.4
2	1	9.1
3	1	9.1
4	2	18.2
5	1	9.1
6	2	18.2
Subjective Rating of Health		
Poor	1	9.1
Fair	2	18.2
Good	8	72.7
Type(s) of Lupus		
Systemic Lupus Erythematosus	9	81.2
Systemic Lupus Erythematosus/Lupus Nephritis	1	9.1
Cutaneous Lupus Erythematosus	1	9.1
Lupus Damage		
Transverse Myelitis	1	9.1
Transverse Myelitis, Seizure, Cataract	1	9.1
Cataract	1	9.1
Lupus QOL Sum		
50-70	2	18.2
71-91	2	18.2
92-112	1	9.1
113-133	2	18.2
134 and above	4	36.4
SLENQ Sum		
40-60	4	36.4
61-81	3	27.3
125 and above	4	36.4

APPENDIX B

SUMMARY OF THEMATIC FINDINGS

Table 2. Summary of Thematic Findings

Themes and subthemes	**Participants quotes**
1. Difficulties with Diagnosis	
1.1. Delay of diagnosis	*So I was actually not formally diagnosed with lupus until…14 years later*
1.2. Misdiagnosis	*…they thought I was in a car accident or that someone or something had hit me…*
1.3. Fighting for diagnosis	*…leading up to the diagnosis…it took a lot of fighting on my part*
2. Discovering Lupus is a Process	
2.1. Fatigue/Pain	*…there's no day without pain…*
2.2. Unpredictable nature of lupus	*… I never know if I'm…normal sick or…if it's the lupus.*
2.3. Feelings of inadequacy & depression	*…I got really depressed because…I was told that I couldn't do a lot of things anymore*
2.4. Accepting that lupus has limitations	*…you can do anything like anybody else. It's just you can do it differently.*
3. Managing Lupus	
3.1. Planning ahead because of symptoms	*…just staying out of the sunlight because…the sun really irritates my skin.*
3.2. Listening to one's own body	*…I basically…just plan to rest.*
3.3. Lack of information about lupus	*…lupus is an enigma…there are so many symptoms and…so many different things going on.*
3.4. Navigating the Internet for information about lupus	*…it's hard to look online when there's a lot of [crap] online.*
3.5. Learning from other patient experiences	*…[I look up] exercises for rheumatoid arthritis patients...*

Table 2 (continued). Summary of Thematic Findings

Themes and subthemes	**Participant quotes**
4. Social Impact	
4.1. Instrumental and emotional social support	*…they just do…everyday things for me.*
4.2. General lack of awareness about lupus	*…normal people can't fathom having pain all the time.*
5. Communicating the Experience	
5.1. Educating others about lupus	*Find those phrases that become meaningful to you and your friends*
5.2. Relating information in ways others can understand	*…it's like you're having the flu but without mucus and coughing.*
5.2.1. Spoon Theory	*…with lupus you wake up in the morning with [for example] 15 spoons. And everything that you do takes off one spoon.*
6. Limitations with the Healthcare System	
6.1. Difficulty getting appointments	*...it takes 4 to 5 months to get in if you're a new patient…*
6.2. Problems with doctors	*I had doctors accuse me…that this was in my head and…it wasn't actual pain.*
6.3. Finding new doctors	*…if there is one thing you do and all that week, find another doctor…*
6.4. Partnering with doctors	*…[my doctor] gave me his cell phone number…so…I could call him at any time.*

APPENDIX C

SEMI-STRUCTURED INTERVIEW QUESTIONS

Thank you very much for agreeing to the interview, we believe that the information you share with us, can help us understand the lived experience of patients with lupus, and maybe develop better strategies to help them. **Let's start with your own story. How did it start?**

- How long were you experiencing symptoms before you were diagnosed?
- What type of symptoms did you initially experience?
- Can you tell me about thoughts/worries you were having during the process of being diagnosed?
- What has been the most challenging aspect of having lupus?
- What advice would you give somebody that is in the initial stages of being diagnosed with lupus?

Can you tell me about your experience with lupus-related symptoms?

- How do you deal with the symptoms?
- How has that affected your life?
- Do you feel others understand your experience of having lupus?
- Can you tell me how you explain your experience of having lupus to others?
- What advice would you give somebody that is in the initial stages of being diagnosed with lupus regarding how to communicate with others about your illness and/or symptoms?

Managing SLE can be overwhelming for some people. When your symptoms get worse, what do you do?

- Do you have somebody who can help when the going gets tough?
- How do others help you manage your condition?
- What do they do for you that helps?
- What would you like them to do that will make your life easier/better? What advice would you give somebody just diagnosed with lupus regarding how to manage the condition?

How would you describe your working relationship with your doctor?

Who would you say has been your best ally in the healthcare system?

- Can you describe how you developed this partnership?
- Did you see many healthcare professionals before finding this person?
- What qualities make this person good? Can you talk about the problems/difficulties you experienced with other providers?
- What advice would you give somebody that is in the initial stages of being diagnosed with lupus regarding how to find the right person to help?

What do you think about the quality of information you have received about lupus care from healthcare professionals?

- Has the quality changed since you were initially diagnosed?

If you had any other advice for someone just diagnosed, what would it be?

Is there anything else you'd like to add related to what we've discussed?

APPENDIX D

SURVEY

The following questionnaire asks about information related to your health, health care practices, and health needs. There are no right or wrong answers. First, we need to know a little about you.

Current Age: _____

Race/Ethnicity: _____

Please check which best describes your current relationship status (check all that ap ply):

- ○ **Single**
- ○ **In a relationship, not living together**
- ○ **In a relationship, living with romantic partner**
- ○ **Married**
- ○ **Previously married; now separated**
- ○ **Previously married; now divorced**
- ○ **Previously married; now widowed**
- ○ **Other (please specify):**

Are you currently…? Check all that apply

- ○ **Employed full-time**
- ○ **Employed part-time**
- ○ **Employed for wages**
- ○ **Self-employed**
- ○ **Out of work for more than 1 year**
- ○ **Out of work for less than 1 year**
- ○ **A homemaker**
- ○ **A full time student**
- ○ **Retired**
- ○ **On disability**

What is the combined (before taxes) family income for your household from all sources? Please mark one.

- ○ **Yearly income of $10,000 or less**
- ○ **$10,001- $20,000**
- ○ **$20,001- $30,000**
- ○ **$30,001- $40,000**
- ○ **$40,001 - $50, 000**
- ○ **$50,001 - $60, 000**
- ○ **$60,001 - $70, 000**
- ○ **$70,001 and up**
- ○ **I do not know/ refuse**

How many members are in your household including yourself? _____

Would you say that in general your health is:

- ○ **Excellent**
- ○ **Very good**
- ○ **Good**
- ○ **Fair**
- ○ **Poor**

Age of lupus diagnosis: _____

What type(s) of lupus do you have?

BILD

This survey collects information about symptoms you may have experienced related to your lupus. In each box, please check "Yes" if you have experienced such symptoms, "No" if you have not experienced such symptoms, or leave blank if you are unsure.

Ocular	Yes	No
Has a doctor ever told you that you had any of the following conditions or symptoms?		
1. Has an eye doctor ever told you that you had something wrong with the retina of your eye because of your lupus? (*note: The retina is the back of your eye*)		
2. A cataract in your eye?		
Neuropsychiatric		
3. A psychotic episode?		
4. Seizures?		
If yes: Did you ever have to take medication for seizures for at least 6 months?		
5. Stroke?		
If yes: Did you ever have more than 1 stroke at least 6 months apart?		
6. Paralysis in your arms or legs that was so severe that you needed to be hospitalized? *(note: This is transverse myelitis, a rare condition caused by inflammation of the spinal cord).*		
If yes: Was this paralysis from a stroke or multiple sclerosis?		
Renal		
7. Have you ever had a kidney transplant?		
8. Have you ever been on dialysis?		
Pulmonary		
Has a doctor ever told you that you had any of the following conditions or symptoms?		
9. Pulmonary hypertension, which is high blood pressure in the lungs? This is different from regular hypertension or high blood pressure.		
10. A serious condition of your lungs, such as fibrosis or interstitial lung disease? This does *not* include pneumonia, asthma, emphysema, or pleurisy. *(note: also not COPD, or bronchitis)*		

Cardiovascular		
11. Have you ever had coronary or heart bypass surgery?		
Have you ever been told by a doctor that you had any of the following problems?		
12. Heart disease, including angina or congestive heart failure?		
13. Heart attack?		
If yes: Did you ever have more than 1 heart attack at least 6 months apart?		
14. An episode of pericarditis, which is an inflammation in the sack around the heart, that lasted 6 months or longer?		

Lupus QoL – The following questions ask about the day-to-day problems that can affect SLE patients. There are no right or wrong answers. Mark an X in the box that best demonstrates its importance in your life.

How difficult has each of these activities been in the last week as a result of your SLE?								
	Not difficult at all	Hardy difficult	Somewhat difficult	Moderately difficult	Quite difficult	Very difficult	Extremely difficult	N/A
1. Walking outdoors on level ground.								
2. Shopping.								
3. Turning taps on and off (or faucets) on and off.								
4. Going to the supermarket (grocery store).								
5. Bathing and drying yourself.								
6. Walking 2 miles.								
How troubled have you been in the last week by each of these social or occupational activities as a result of your SLE?								
	Not troubled at all	Hardly troubled	Somewhat troubled	Moderately troubled	Quite troubled	Very troubled	Extremely troubled	N/A
7. Work and school performance.								

8. Interference with your career or education.								
9. Missing work or school.								
10. Relationship with friends and relatives.								
11. Taking part in sports.								
12. Sexual activities.								
13. Taking part in social activities.								
14. Unable to go out in the sun.								
15. Earning/making less money because I have SLE.								

How troubled have you been by each of these symptoms in the last week as a result of your SLE?								
	Not troubled at all	Hardly troubled	Somewhat troubled	Moderately troubled	Quite troubled	Very troubled	Extremely troubled	N/A
16. Poor memory.								
17. Loss of appetite.								
18. Fatigue.								
19. Poor concentration.								
20. Itchy skin.								
21. Sore mouth.								
22. Sore, painful, or stinging skin.								
23. Joint pain and swelling.								
How troubled have you been by each of these problems related to medical treatment in the last week as a result of your SLE?								
	Not troubled at all	Hardly troubled	Somewhat troubled	Moderately troubled	Quite troubled	Very troubled	Extremely troubled	N/A
24. Fear of needles.								
25. Dietary restrictions.								
26. Inconvenie								

nce of daily medication.								
27. Inconvenience of frequent clinic visits.								
How often during the last week have you been troubled by these emotions as a result of your SLE?								
	Not at all	Hardly ever	Somewhat often	Moderately often	Quite often	Very often	Extremely often	N/A
28. Self-consciousness.								
29. Feeling low or down.								
30. Depression.								
31. Anxiety.								

How often in the last week have you been troubled by these feelings as a result of your SLE?								
	Not at all	Hardly ever	Somewhat often	Moderately often	Quite often	Very often	Extremely often	N/A
32. I wish that other people did not know that I have SLE								
33. Being made fun of by my friends and colleagues.								

34. Low self-esteem.								
35. Embarrassment about my SLE.								
36. Concern about the financial burden to my family.								
37. Concern that medicines do not work.								
38. Concern about side effects of medicines.								
39. Fear of receiving bad news from doctors.								
40. Consuming more alcohol or tobacco.								

SLENQ

The following questions ask about your need for support or care regarding your lupus condition. Indicate the extent and magnitude of your need for support or care **in the previous 6 months** using a 5-point scale: (1 = "no need," 2 = "need already satisfied," 3 = "low need," 4 = "moderate need" and 5 = "high need")

	No need	**Need already satisfied**	**Low need**	**Moderate need**	**High need**
Physical					
Tiredness					
Pain					
Sleeping problems					
Headaches					
Skin rashes					
Dry mouth					
Shortness of breath					
Mouth ulcers					
Urinary frequency					
Dental health					
Daily Living Issues					
Work around home					
Shopping					
Food preparation					
Driving difficulty					
Writing problems					
Transport to appointments					
Speaking problems					
Reading difficulties					

	No need	Need already satisfied	Low need	Moderate need	High need
Psychological/Spiritual/Existential					
Unable to do what used to do					
Fears disease flare					
Anxiety and stress					
Feeling down/depressed					
Fears physical disability					
Uncertainty about future					
Changes in appearance					
Keeping positive outlook					
Feeling in control					
Feeling useless					
Health Services					
Reassurance of normality					
Open discussion with doctors					
Knowing when to see doctor					
Talking to a professional					
Rapid test result information					
Concerns to be taken seriously					
Information about treatment effects					
Discussion time with doctors					

General practitioner understanding SLE					
Selecting medical help					

	No need	**Need already satisfied**	**Low need**	**Moderate need**	**High need**
Health Information					
Information services and benefits					
Guidance on disease phase activity					
Obtaining self-help information					
Support for complementary therapy					
Relaxation classes					
Dietary information					
Getting written information					
Obtaining current information					
Drop in counseling					
Counseling services					
Social Support					
Explaining SLE unpredictability					
Others coping with SLE					

Ability to participate in social activity					
Expressing feeling with others					
Coping with attitude changes to self					
Support from partner/children					
Maintaining friendships					
Maintaining family relationships					
Coping with change in sexual relations					
Sexual information for partner					
Employment					
Meeting extra costs of disease					
Meeting living expenses					
Maintaining job performance					
Gaining employment					

APPENDIX E

INFORMED CONSENT

Consent Form for Participation in a Research Study

Arizona State University

Lived experiences of women with systemic lupus erythematosus (SLE)

Description of the research and your participation

You are invited to participate in a research study conducted by Perla Vargas (PhD) and Miriam Vélez-Bermúdez (BS). You must be a female 18 years or older to participate, and have been officially diagnosed with lupus by a physician for at least one year prior to December 2015.
The purpose of this research is to learn about the lived experiences of living with lupus in terms of support and physician care.

Your participation will involve answering face-to-face interview questions about your illness and the support you receive. This may take 30 minutes to 3 hours, depending on your personal experience and the information you are willing to share. We would like to audio record the interview to look at the data more closely. Please let us know if you do not want to be audio recorded. You can change your mind after we start, just let the researchers know. Following the interview, you will be asked to complete a survey with questions related to your illness, health needs, and health behaviors. This may take 10 – 20 minutes to complete.

Risks and discomforts

There are certain risks or discomforts associated with this research. They include being inconvenienced by taking the time to answer survey and interview questions. You may also experience discomfort when asked about your personal thoughts and feelings. Keep in mind you may withdraw from the study at any time, and you may refuse to answer any question if you wish.

Potential benefits

This research may help us to further understand certain risks and protective factors among women with SLE in terms of support. There are no known direct benefits to you as a result of your participation in this research. ASU West students participating in the study will receive SONA credits for their time. Each participant will receive 1 research credit for every 30 minutes or part of 30 minutes used for the interview. In other words, if the interview takes 45 minutes you will receive 2 research credits plus 1 credit for the time it takes to get to and from the location used for the interview.

Protection of confidentiality

All answers will be kept confidential. Your contact information will not be linked to the interview or the data from the questionnaires. No visual images will be taken. All audio recordings will be deleted two weeks following transcription. All data will be kept on a password protected computer, in a locked laboratory of the principal investigator. We will do everything we can to protect your privacy. Your identity will not be revealed in any publication resulting from this study.

Voluntary participation

Your participation in this research study is voluntary. You may choose not to participate and you may withdraw your consent to participate at any time. You will not be penalized in any way should you decide not to participate or to withdraw from this study.

Contact information

If you have any questions or concerns about this study or if any problems arise, please contact Perla Vargas at 602-543-8224 or Miriam Vélez-Bermúdez at 614-678-2127. If you have any questions or concerns about your rights as a research participant, please contact the Arizona State University Institutional Review Board at 480-965-6788.

Consent

Your participation in the interview and filling out the questionnaire is considered your consent to take part in this research

APPENDIX F

IRB EXEMPTION LETTER

EXEMPTION GRANTED

Perla Vargas
Social and Behavioral Sciences, School of
602/543-8224
Perla.Vargas@asu.edu

Dear Perla Vargas:

On 12/11/2015 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Factors mediating patient-doctor relationship among women with systemic lupus erythematosus
Investigator:	Perla Vargas
IRB ID:	STUDY00003576
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Script inviting participation, Category: Recruitment Materials; • Consent form, Category: Consent Form; • HRP-503a-TEMPLATE_PROTOCOL_SocialBehavioralV02-10-15.docx, Category: IRB Protocol; • Interview questions, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions); • Questionnaire for participants, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 12/11/2015.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Miriam Velez-Bermudez
Miriam Velez-Bermudez
Agnes Bucko